Orienting child- and family-centered care toward equity

Alison Gerlach[1] and Colleen Varcoe[2]

Abstract

Child- and family-centered care (CFCC) is being increasingly adopted internationally as a fundamental philosophical approach to the design, delivery, and evaluation of children's services in diverse primary and acute health care contexts. CFCC has yet to be explored in the context of families and children whose health and health care is likely to be compromised by multifaceted social and structural factors, including racialization, material deprivation, and historically entrenched power imbalances. To date, an equity orientation for CFCC has not been examined or developed. This is a critical area of inquiry, given the increasing evidence that children in families who face such inequities have poor health outcomes. This article examines dominant discourses on CFCC in the context of families and children who are at greater risk of health inequities in wealthy countries, drawing on Canada as a useful example. It outlines an evidence-based approach to equity-oriented care that the authors contend has the potential to orient CFCC toward equity and provide greater clarity in the conceptualization, implementation, measurement, and evaluation of CFCC in ways that can benefit all families and children including those who have typically been excluded from research.

Introduction

Child- and family-centered care (CFCC) is being increasingly adopted internationally, including in Canada, as a fundamental philosophical approach to the design, delivery, and evaluation of children's services in diverse primary and acute health care contexts (Coyne et al., 2016; Dennis et al., 2017; Kuo et al., 2012; Power and Franck, 2008), including in the provision of pediatric

[1] School of Child and Youth Care, Faculty of Human and Social Development, University of Victoria, Canada
[2] School of Nursing, The University of British Columbia, Canada

Corresponding author:
Alison Gerlach, School of Child and Youth Care, Faculty of Human and Social Development, University of Victoria, PO Box 1700, STN CSC, Victoria V8W 2Y2, BC, Canada.
Email: alisongerlach@uvic.ca

emergency care (Child Health BC, 2016; Dudley et al., 2015; Sick Kids, 2014). Currently there is a lack of consensus on what constitutes CFCC, and how "children" are situated within family-centered care (Al-Motlaq et al., 2018). Common elements of CFCC include health care providers listening to and honoring families and children's perspectives and choices such that their knowledge, priorities, and beliefs are incorporated into the planning and delivery of care and providing timely and accessible information that affirms and fosters their participation in care and decision-making at a level of their choosing (Byczkowski et al., 2015; Conway et al., 2006; Dennis et al., 2017; Ehrich et al., 2015; Institute for Patient- and Family-Centered Care, 2018; Kuo et al., 2012). CFCC builds on the idea of family-centered care and is argued to extend the latter in important ways that take into account children's agency (Coyne et al., 2016; Einboden et al., 2013b) and human rights to participate in health care decisions that affect them (Coyne et al., 2016; Ford, 2017; Grahn et al., 2016). However, the extent to which CFCC can address shortcomings of family-centered care has not been established. According to the extant literature, CFCC has yet to be explored in the context of families and children whose health and health care is likely to be compromised by multifaceted social and structural factors, including racialization, material deprivation, and historically entrenched power imbalances. This is a critical area of inquiry, given the increasing evidence that children in families who face such inequities have poor health outcomes (Bell et al., 2013; Boyce and Hertzman, 2018; Carter, 2018; Durkin and Yeargin-Allsopp, 2018; Liming and Grube, 2018; Shonkoff, 2012). Despite the lack of consensus regarding what constitutes CFCC, and to date, the inattention to the relationship of CFCC to social and economic inequities, we contend that this approach has considerable potential for promoting health and health care inequities. The emphasis on agency and participation of both children and their caregivers provides important grounding essential to an equity orientation.

This article examines dominant discourses of CFCC in the context of families and children who are at greater risk of health inequities in wealthy countries, drawing on Canada as a useful example. As a country structured by race-based colonialism, the economic and social positions of families and children who are Indigenous, or who have come to Canada as immigrants or refugees and are racialized within the white-dominated society are instructive to many colonial countries where inequities are widening along these dimensions. This article also outlines an evidence-based approach to equity-oriented care that the authors contend has the potential to orient CFCC toward equity and provide greater clarity in the conceptualization, implementation, measurement, and evaluation of CFCC in ways that can benefit all families and children including those who have typically been excluded from research.

Childhood adversity and health inequities

The former Chair of the World Health Organization's (WHO) Commission on Social Determinants of Health, Sir Michael Marmot (2011) has called for "equity for every child from the start" as a fundamental aspect of addressing health inequities within and between countries (p. 702). The WHO defines health equity (World Health Organization, 2008) as the absence of systematic and remediable differences in one or more characteristics of health across socially, economically, or demographically defined populations or population groups. Health equities are closely connected to the distribution of power and wealth within a society and the social conditions in which people live (World Health Organization, 2008). Health inequities are thus "unfair, avoidable, and remediable differences in health status between countries and between different groups of people within the same country" (World Health Organization, 2013).

Children's experiences of health and health care inequities are structurally rooted in and continuous with the impacts of intersecting social determinants on their family's everyday lives and well-being (Gerlach et al., 2018). From this perspective, addressing child health and health care inequities is inseparable from engaging with and supporting the well-being of the family as a whole; recognizing the diversity of what can constitute "family" in contemporary societies. Addressing children's experiences of health and social inequities, particularly from the prenatal period to age five, is of critical concern because they can result in an increased risk of poor health outcomes and adverse life experiences across their life course (Bell et al., 2013; Boyce and Hertzman, 2018).

Globally, in diverse contexts, there is increasing evidence that health and health care inequities are significantly and positively correlated with experiences of racialization, socioeconomic inequities, and systemic and interpersonal discrimination (Allan and Smylie, 2015; Bastos et al., 2018; Fitzsimons et al., 2017; Marmot, 2013; Philbin et al., 2018; Wilson et al., 2017). In Canada, child populations that are particularly vulnerable to health inequities include children in lone parent families led by women (Gurstein and Vilches, 2011); children in "state care" (Representative for Children and Youth, 2014); Indigenous children (Blackstock, 2016; Smylie et al., 2010; Stewart et al., 2013); and children in families who experience racialization, stigma, and/or social marginalization (Dunn and Dyck, 2000; Representative for Children and Youth and Office of the Provincial Health Officer, 2015). In the Canadian context, a stark example of health inequities is evident in the country's differing rates of infant mortality in the first year of life, which is recognized worldwide as a fundamental indicator of the well-being of a society. The average infant mortality rate in Canada is estimated to be 4.4 infant deaths/1000 in their first year of life. For families living in Inuit Nunangat, the homeland of the Inuit in Canada, the rate is estimated to be 12.2 infant deaths/1000 live births (Inuit Tapiriit Kanatami, 2018). This higher rate is largely due to potential remediable structural inequities, rooted in historical and ongoing colonialism, that result in many Inuit families lacking basic determinants of health including housing and food security for their children in their first year of life (Inuit Tapiriit Kanatami, 2014).

It is also important to note that as gatekeepers to their children's health, when parents feel disempowered, judged, or traumatized in health care encounters, they can constrain their children's access to equitable health outcomes and care (Allan and Smylie, 2015). In the context of Indigenous families in Canada, the ongoing effects of the residential school system and contemporary child welfare system are significant barriers to families feeling safe to engage with child health care and related services (Gerlach et al., 2017a; Health Council of Canada, 2011). For example, some Indigenous families report not feeling safe taking their children to an emergency department without having a trusted person with them as they anticipate that they will be treated poorly (Gerlach et al., 2017a, 2017b). Some Indigenous women report avoiding care for themselves, thus worsening their own and potentially their children's health, in fear that their children might be apprehended by the state (Denison et al., 2014).

Participation as a key element of child- and family-centered care

In recent years, a philosophical shift from "family-centered care[1]" to CFCC aligns with a growing recognition of children as social agents (Coyne et al., 2016; Einboden et al., 2013a; Einboden et al., 2013b) and international calls to uphold children's rights to participate[2] in health care decisions that affect them (Ehrich et al., 2015; Ford, 2017; Grahn et al., 2016). Key elements of CFCC include health care providers: (1) listening to and honoring families and children's perspectives and choices such that their knowledge, priorities, concerns, and beliefs are incorporated into the planning and

delivery of care; (2) providing families and children with timely and accessible information in ways that are affirming and foster their participation in care and decision-making; and (3) supporting families and children's participation in care and decision-making at a level of their choosing (Byczkowski et al., 2015; Conway et al., 2006; Dennis et al., 2017; Ehrich et al., 2015; Institute for Patient- and Family-Centered Care, 2018; Kuo et al., 2012).

Health systems and policies that support children's participation are increasingly viewed as essential for optimizing children's health and health care outcomes (Davies and Randall, 2015; Ehrich et al., 2015; Moore and Kirk, 2010), improving families' experiences of care and staff satisfaction, and a wiser allocation of resources (Institute for Patient- and Family-Centered Care, 2018). Evidence points to some children preferring to be included in interactions and decisions about their care, with physical and psychological benefits as children gain more knowledge about their health condition and a greater sense of self-determination (Coyne et al., 2016; Jones et al., 2012). Children who participate in their own care may also experience less pain and discomfort than children who are not involved (Grahn et al., 2016). Involving family members in providing essential physical, social, and emotional support in pediatric emergency care is also associated with improvements in children's recovery and health outcomes (Brysiewicz, 2017).

Evidence indicates, however, that while CFCC is evident within the rhetoric and motives of pediatric care policies, its implementation is highly variable (Coyne, 2008; Dennis et al., 2017; Ehrich et al., 2015; Hemingway and Redsell, 2011; Jeremic et al., 2016; Kuo et al., 2012; Moore and Kirk, 2010). Child and parent participation is a complex endeavor influenced by multiple and intersecting factors including whether and how health care providers include children and parents in decision-making (Aarthun et al., 2018) and how relational processes of care are shaped by inherent clinician–patient power imbalances (Berry et al., 2017; Shields et al., 2012). For children, their agency and participation can also be shaped by the adults present, both parents and health care providers, who may have differing opinions about children's care-related decisional capacity and the preferred extent of their involvement (Davies and Randall, 2015; Jeremic et al., 2016; Rasmussen et al., 2017). Factors that constrain physicians' facilitation of children's participation can include lack of time, loss of power and control, and uncertainty about children's competence related to their age (Coyne, 2008; Ehrich et al., 2015).

CFCC discourses tend to reflect and reproduce Euro-western values and assumptions about participation, predominately from the perspectives of middle class health care professionals located in predominately urban settings (Alabdulaziza et al., 2017; Foster and Whitehead, 2017; Jeremic et al., 2016; Jessup et al., 2017; Smith et al., 2017). The relevancy, ethics, and efficacy of implementing CFCC in diverse sociocultural, economic, and geographical contexts have yet to be adequately explored. Moreover, there is a paucity of critical analysis on how CFCC is, or could be, inclusive of and responsive to the priorities and preference of parents and children with diverse social identities, locations, and circumstances (Shields et al., 2012; Wood and Goldhagen, 2013) that can profoundly shape access to equitable health and health care. Critical engagement with CFCC is therefore required in order to resist essentialized views of CFCC being applied universally and failing to address child health and health care inequities (Wilson et al., 2017), and to resist CFCC being seen as a panacea for the limitations of family-centered care.

Orienting child- and family-centered care toward equity

The field of research into health equity is well established (Rasanathan and Diaz, 2016). However, evidence about how health care systems can contribute toward preventing and mitigating *child*

health inequities is in its infancy in Canada (Gerlach et al., 2018; Lynam et al., 2011) and internationally (Goldhagen et al., 2015; Morrison et al., 2017; Marmot, 2011; Schleiff et al., 2017).

In Canada, some pediatric institutions claim that CFCC is central to achieving health equity (Sick Kids, 2014). However, there is limited knowledge on how parents' social identities shape their children participation in care (Coyne, 2008) and a paucity of research on CFCC that is inclusive of the perspectives of families who are at greater risk of health and health care inequities. As discussed, CFCC is a participatory, dynamic, and relational process. However, what participation looks like has not been adequately explored. Moreover, participation has not been explored at all from the perspectives of families who may be reluctant to access health care for their children for a variety of reasons, including parental concerns related to social marginalization, anticipated stigma and discrimination, and previous negative interactions within health care settings. Thus, while CFCC has been promoted as essential and linked to fostering equity, an equity orientation has not been examined or developed. Indeed, according to the extant literature, CFCC has yet to be explored with families and children who are vulnerable to health inequities as a result of multifaceted personal, social, and structural factors. Consequently, there is a need to expand the conceptualization and application of CFCC toward equity.

The aim of CFCC is to reframe the relationships in pediatric health care in recognition of families *and* children being 'essential allies' in direct care interactions, quality improvement initiatives, organizational design, and policy development (Curran et al., 2018; Institute for Patient- and Family-Centered Care, 2018). Relational approaches that support child and family participation in decision-making and care are central to CFCC and well aligned with the prevailing ideology of patient involvement in health care reform in Canada and internationally (Laurance et al., 2014; Manafo et al., 2018). Relational approaches are built on an understanding of how people mutually influence one another and their environments and require taking the contexts of people's lives and health care into account in health care practice (Doane and Varcoe, 2015; Hartrick Doane, 2015; Varcoe and Doane, 2015).

Relational approaches and participation in decision-making and care have been shown as central to equity-oriented care with primarily adult populations (Browne et al., 2018). EQUIP Health Care (https://equiphealthcare.ca/) is an evidence-informed approach codeveloped by Varcoe and colleagues (Browne et al., 2012, 2016). EQUIP research is the first to empirically show that people living in marginalizing conditions who receive equity-oriented care experience improved health outcomes over time; the extent to which they experience care as equity-oriented, predicts a higher level of confidence and comfort with the care they receive, which in turn predicts their own comfort and confidence in managing and preventing their own health problems, which is associated with better quality of life, lower depressive symptoms, fewer trauma symptoms, and less disabling chronic pain (Ford-Gilboe et al., 2018).

EQUIP is centered on three key dimensions: cultural safety, trauma- and violence-informed care (TVIC), and harm reduction, all of which must be tailored to the context (Browne et al., 2015, 2016, 2018; Ford-Gilboe et al., 2018; Wong et al., 2014). **Cultural safety** focuses on addressing structural conditions to support changes to dominant norms to enhance care for everyone, not just those presumed to be "different" (Browne et al., 2015; Gerlach, 2012; Varcoe and Browne, 2015). **TVIC** is an approach to policy and practice interventions developed by Varcoe and colleagues to minimize harm and promote healing by understanding experiences of past and ongoing interpersonal and structural violence as causes of trauma and taking action at health care practice and organizational levels and as a society (Ponic et al., 2016; Varcoe et al., 2016). **Harm reduction** involves practices

that mitigate harms of substance use and harms associated with the historical, sociocultural, and political determinants of drug use and drug and health policy (Smye et al., 2011).

These three key dimensions have yet to be explored in research examining CFCC. It has been proposed that cultural safety and TVIC are central to providing Indigenous mothers in Canada with equitable access to family-centered primary health care for their infants (Wright et al., 2019) Also, research in the Canadian context led by the primary author indicates the relevancy of the dimensions of EQUIP for Indigenous families and children whose equitable access to health and health care are compromised as a result of intersecting social and structural factors [references removed for anonymity].

Each of the key dimensions of equity-oriented care described above has patient participation as a central tenet (Gerlach et al., 2018, 2017a; Ponic et al., 2016; Smye et al., 2011; Varcoe and Browne, 2015). This, taken together with the shifts heralded by the move from family-centered to CFCC, indicates a foundational understanding is required regarding what would be needed to address each of these key dimensions in pediatric health care. Importantly, the key dimensions can not only orient CFCC toward equity but also provide greater conceptual clarity related to discussions on what constitutes CFCC and direction on how to implement, measure, and evaluate CFCC. For example, informing CFCC from a cultural safety perspective has the potential to promote efforts to reduce and mitigate the impact of systemic and interpersonal racism and provides a basis for developing trusting relationships when racism is an ongoing threat to well-being. Moreover, a recent dissertation focused on cultural safety in the context of child health in Aotearoa/New Zealand suggests that Maori and Pacific whanau approaches could prompt a fundamental restructuring of health care for families and children (Brown, 2018). Similarly, employing a lens of TVIC to how CFCC is conceptualized and enacted can inform relational practices that have the potential to mitigate multigenerational impacts of historical and ongoing interpersonal violence that often affect the well-being of those experiencing structural inequities and provide a foundation for relationships based on understandings of families' life circumstances, histories, and traumatic experiences. Finally, applying a harm reduction philosophy and approach to CFCC, not only to parents with problematic substance use but also as a lens on prevention of such problems, can help attenuate the harms of stereotyping related to substance use that families encounter, with impacts on their access and quality of health care. Importantly, this approach can help mitigate children's health care inequities as a result of their parents' reluctance to access care for fear of stigma, stereotyping, or state child apprehension.

Taken together the key dimensions of equity-oriented care based on EQUIP research have the potential to inform how CFCC can be tailored in response to the social contexts and complexities of families and children's lives and inform relational practices that mitigate power imbalances in patient–provider relationships and promote the development of trusting relationships. Such relational approaches are supported by evidence that trusting patient–health care provider relationships can result in increased patient participation in care (Murray and McCrone, 2015). Orienting CFCC toward equity based on the key dimensions outlined above also provides greater clarity for measuring and evaluating its impact in ways that can benefit all families and children including those who have typically been excluded from research.

Conclusion

The provision of CFCC is a complex process that continues to lack empirical evidence, conceptual clarity, and consensus regarding its implementation. As highlighted in this article, there is also a scarcity of evidence in Canada and internationally on how health care services that claim to be

child- and family-centered are/can be responsive to families and children who experience a greater risk of health and health care inequities. This article outlines a potential evidence-based approach to orient CFCC toward equity that has the potential to clarify its conceptualization, implementation, measurement, and evaluation. Given the growing recognition for socially responsive and inclusive health care approaches that mitigates the impacts of childhood adversity across the life course, this article suggests that there is an immediate need for research on how CFCC can be inclusive of and responsive to families and children who are vulnerable to health and health care inequities. There is also a need for further research that recognizes children's agency and methodologies that are inclusive of children as coresearchers and participants.

Declaration of Conflicting Interests

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ORCID iD

Alison Gerlach https://orcid.org/0000-0002-2720-6768

Notes

1. Some conceptualizations of "family-centered care" include the role and participation of children. For the purposes of this article and consistent with exploring issues of equity and children as social agents, the term child- and family-centered care is used.
2. "Participation" has been conceptualized and used differentially in numerous studies (Murray and McCrone, 2015). For the purposes of this article, the term participation is used broadly as a way of describing parents and children's contributions within health care consultations or discussions about them; acknowledging that the extent to which a child can participate will vary depending on multiple factors including their age and health care needs.

References

Aarthun A, Øymar, KA and Akerjordet K (2018) How health professionals facilitate parents' involvement in decision-making at the hospital: a parental perspective. *Journal of Child Health Care* 22: 108–121.

Alabdulaziz H, Moss C and Copnell B (2017) Paediatric nurses' perceptions and practices of family-centred care in Saudi hospitals: a mixed methods study. *International Journal of Nursing Studies* 69: 66–77.

Al-Motlaq MA, Carter B, Neill S, et al. (2018) Toward developing consensus on family-centred care: an international descriptive study and discussion. *Journal of Child Health Care* 23: 458–467.

Allan B and Smylie J (2015) *First Peoples, Second Class Treatment: The Role of Racism in the Health and Well-Being of Indigenous Peoples in Canada*. Canada: Wellesley Institute. Available at: http://www.wellesleyinstitute.com/wp-content/uploads/2015/02/Report-First-Peoples-Second-Class-Treatment-Final.pdf (accessed 5 June 2015).

Bastos JL, Harnois CE and Paradies YC (2018) Health care barriers, racism, and intersectionality in Australia. *Social Science & Medicine* 199: 209–218.

Bell R Donkin A and Marmot M (2013) *Tackling Structural and Social Issues to Reduce Inequities in Children's Outcomes in Low-to Middle-Income Countries, Office of Research Discussion Paper No.2013-02*. Florence, Italy: UNICEF Office of Research.

Berry LL, Danaher TS, Beckham D, et al. (2017) When patients and their families feel like hostages to health care. *Mayo Clinic Proceedings* 92: 1373–1381.

Blackstock C (2016) Toward the full and proper implementation of Jordan's principle: an elusive goal to date. *Paediatrics and Child Health* 21: 245–246.

Boyce WT and Hertzman C (2018) Early childhood health and the life course: the state of the science and proposed research priorities. In: Halfon N, Forrest CB, Lerner RM, et al. (eds). *Handbook of Life Course Health Development*. Cham, Switzerland: Springer.

Brown RM (2018) *Surviving the system: Māori and Pacific whānau coping strategies to overcome health system barriers*. PhD Thesis, Auckland University of Technology, New Zealand.

Browne AJ Varcoe C, Ford-Gilboe M, et al. (2015) EQUIP healthcare: an overview of a multi-component intervention to enhance equity-oriented care in primary health care settings. *International Journal for Equity in Health* 14: 1–11.

Browne AJ, Varcoe C, Ford-Gilboeboe M, et al. (2018) Disruption as opportunity: impacts of an organizational health equity intervention in primary care clinics. *International Journal for Equity in Health* 17: 1–16.

Browne AJ, Varcoe C, Lavoie J, et al. (2016) Enhancing health care equity with Indigenous populations: evidence-based strategies from an ethnographic study. *BMC Health Services Research* 16: 1–17.

Browne AJ, Varcoe C, Smye V, et al. (2012) Closing the health equity gap: evidence-based strategies for primary health care organizations. *International Journal for Equity in Health* 11(59). DOI: 10.1186/1475-9276

Brysiewicz P (2017) Focusing on families in the emergency department. *Editorial International Emergency Nursing* 30: 1–2.

Byzkowski TL, Gillespie GL, Kennebeck S, et al. (2015) Family-centered pediatric emergency care: a framework for measuring what parents want and value. *Academic Pediatrics* 16: 327–335.

Carter B (2018) Inequality and poverty. *Journal of Child Health Care* 22: 3–5.

Child Health BC (2016) Children's emergency department services: tiers in full support operational planning. Available at: http://childhealthbc.ca/sites/default/files/16%2010%2001%20ED%20Tiers%20in%20Full.pdf

Conway J, Johnson B, Edgman-Levitan S, et al. (2006) Partnering with patients and families to design a patient- and family-centred health care system: a roadmap for the future. Available at: http://www.ihi.org/resources/Pages/Publications/PartneringwithPatientsandFamilies.aspx

Coyne I (2008) Children's participation in consultations and decision-making at health service level: a review of the literature. *International Journal of Nursing Studies* 45: 1682–1689.

Coyne I, Hallström I and Söderbäck M (2016) Reframing the focus from a family-centred to a child-centred care approach for children' healthcare. *Journal of Child Health Care* 20: 494–502.

Curran JA, Bishop A, Chorney J, et al. (2018) Partnering with parents to advance child health research. *Healthcare Management Forum* 31: 45–50.

Davies A and Randall D (2015) Perceptions of children's participation in their healthcare: a critical review. *Issues in Comprehensive Pediatric Nursing* 38: 202–221.

Denison J, Varcoe C and Browne AJ (2014) Aboriginal women's experiences of accessing health care when state apprehension of children is being threatened. *Journal of Advanced Nursing* 70: 1105–1116.

Dennis C, Baxter P, Ploeg J, et al. (2017) Models of partnership within family-centred care in the acute paediatric setting: a discussion paper. *Journal of Advanced Nursing* 73: 361–374.

Doane GH and Varcoe C (2015) *How to Nurse: Relational Inquiry with Individuals and Families in Changing Health and Health Care Contexts*. Philadelphia, PA: Lippincott Williams & Wilkins.

Dudley N, Ackerman A, Brown KM, et al. (2015) Patient-and family-centred care of children in the emergency department. *Pediatrics* 135: 255–272.

Dunn JR and Dyck I (2000) Social determinants of health in Canada's immigrant population: results from the national population health survey. *Social Science & Medicine* 51: 1573–1593.

Durkin MS and Yeargin-Allsopp M (2018) Socioeconomic status and pediatric neurologic disorders: current evidence. *Seminars in Pediatric Neurology* 27: 16–25.

Ehrich J, Pettoello-Mantovani M, Lenton S, et al. (2015) Participation of children and young people in their health care: understanding the potential and limitations. *The Journal of Pediatrics* 167: 783–784.

Einboden R, Rudge T and Varcoe C (2013a) Image, measure, figure: a critical discourse analysis of nursing practices that develop children. *Nursing Philosophy* 14: 212–222.

Einboden R, Rudge T and Varcoe C (2013b) Producing children in the 21st century: a critical discourse analysis of the science and techniques of monitoring early child development. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 17: 549–566.

Fitzsimins E, Goodman A, Kelly E, et al. (2017) Poverty dynamics and parental mental health: determinants of childhood mental health in the UK. *Social Science & Medicine* 175: 43–51.

Ford A (2017) Do children have the right to contribute to medical decisions about their own care? An analysis of policy and practice in the United Kingdom and the United States. *Health and Human Rights*. Available at: https://www.hhrjournal.org/2017/08/do-children-have-the-right-to-contribute-to-medical-decisions-about-their-own-care-an-analysis-of-policy-and-practice-in-the-united-kingdom-and-united-states/ [Online].

Ford-Gilboe M, Wathen CN, Browne AJ, et al. (2018) How equity-oriented health care impacts health: key mechanisms and implications for primary health care practice and policy. *The Milbank Quarterly* 96: 635–671.

Foster M and Whitehead L (2017) Parent and staff perceptions of parental needs during a child's hospital admission to a paediatric high-dependency unit: a New Zealand study. *Journal of Paediatrics and Child Health* 53: 1167–1175.

Gerlach AJ (2012) A critical reflection on the concept of cultural safety. *Canadian Journal of Occupational Therapy* 79: 151–158. DOI: 10.2182/cjot.2012.79.3.4.

Gerlach, AJ, Browne AJ and Greenwood M (2017a) Engaging Indigenous families in a community-based Indigenous early childhood programme in British Columbia, Canada: a cultural safety perspective. *Health & Social Care in the Community* 25: 1763–1773.

Gerlach AJ, Browne AJ, Sinha V, et al. (2017b) Navigating structural violence with Indigenous families: the contested terrain of early childhood intervention and the child welfare system in Canada. *International Indigenous Policy Journal* 8: 1–23.

Gerlach AJ, Browne AJ and Suto MJ (2018) Relational approaches to fostering health equity for Indigenous children through early childhood intervention. *Health Sociology Review* 27: 104–119.

Goldhagen J, Mercer R, Robinson G., et al. (2015) Establishing a child rights, health equity, and social justice-based practice of pediatrics. *The Journal of Pediatrics* 166: 1098–1099.

Grahn M, Ollsson E and Mansson ME (2016) Interactions between children and pediatric nurses at the emergency department: a swedish interview study. *Journal of Pediatric Nursing* 31: 284–292.

Gurstein P and Vilches S (2011) Re-envisioning the environment of support for lone mothers in extreme poverty. In: Griffin Cohen M and Pulkingham J (eds). *Public Policy for Women: The State, Income Security, and Labour Market Issues*. Toronto, Canada: University of Toronto Press.

Hartrick Doane G (2015) Cultivating relational consciousness in social justice practice. In: Kagan PN, Smith M and Chinn PL (eds). *Philosophies and Practices of Emancipatory Nursing: Social Justice as Praxis*. New York: Routledge.

Health Council of Canada (2011) *Understanding and Improving Aboriginal Maternal and Child Health in Canada: Conversations about Promising Practices across Canada*. Toronto, Canada: Health Council of Canada. Available at: http://publications.gc.ca/collections/collection_2011/ccs-hcc/H174-23-2011-eng.pdf (accessed 20 October 2012).

Hemingway P and Redshell S (2011) Children and young people's participation in healthcare consultations in the emergency. *Department International Emergency Nursing* 19(4): 192–198.

Institute for Patient and Family-Centred Care (2018) What is patient- and pamily-centered care? Available at: http://www.ipfcc.org/about/pfcc.html

Inuit Tapiriit Kanatami (2014) Social determinants of Inuit health in Canada. Available at: https://www.itk.ca/wp-content/uploads/2016/07/ITK_Social_Determinants_Report.pdf

Inuit Tapiriit Kanatami (2018) *Inuit Statistical Profile 2018*. Available at: https://www.itk.ca/wp-content/uploads/2018/08/Inuit-Statistical-Profile.pdf

Jeremic V., Senecal K, Borry P, et al. (2016) Participation of children in medical decision-making: challenges and potential solutions. *Journal of Bioethical Inquiry* 13: 1–10.

Jessup M, Smyth W, Abernethy G, et al. (2017) Family-centred care for families living with cystic fibrosis in a rural setting: a qualitative study. *Journal of Clinical Nursing* 27: 590–599.

Jones S, Wilson V, Kelly M, et al. (2012) How children's rights are constructed in family-centred care: a review of the literature. *Journal of Child Health Care: For Professionals Working with Children in the Hospital and Community* 16: 190–205.

Kuo DZ, Houtrow AJ, Arango P, et al. (2012) Family-centered care: current applications and future directions in pediatric health care. *Maternal and Child Health Journal* 16: 297–305.

Laurance J, Henderson S, Howitt PJ, et al. (2014) Patient engagement: four case studies that highlight the potential for improved health outcomes and reduced costs. *Health Affairs* 33: 1627–1634.

Liming KW and Grube WA (2018) Wellbeing outcomes for children exposed to multiple adverse experiences in early childhood: a systematic review. *Child and Adolescent Social Work Journal* 35: 317–335.

Lynam M, Scott L, Loock C, et al. (2011) The RICHER social pediatrics model: fostering access and reducing inequities in children's health. *Healthcare Quarterly* 14: 41–56.

Manafo E, Petermann L, Mason-Lal P, et al. (2018) Patient engagement in Canada: a scoping review of the 'how' and 'what' of patient engagement in health research. *Health Research Policy and Systems* 16: 1–11.

Marmot M (2011) Global action on social determinants of health. *Bulletin of the World Health Organization* 89: 702.

Marmot M (2013) *Review of Social Determinants and the Health Divide in the WHO European Region: Excutive Summary.* Copenhagen, Denmark: UCL Institute of Health Equity, World Health Organization European Region.

Moore L and Kirk S (2010) A literature review of children's and young people's participation in decisions relating to health care. *Journal of Clinical Nursing* 19: 2215–2225.

Morrison J, Pikhart H and Goldblatt P (2017) Interventions to reduce inequalities in health and early child development in Europe from a qualitative perspective. *International Journal for Equity in Health* 16: 1–9.

Murray B and Mccrone S (2015) An integrative review of promoting trust in the patient-primary care provider relationship. *Journal of Advanced Nursing* 71: 3–23.

Philbin MM, Flake M, Hatzenbuehler ML, et al. (2018) State-level immigration and immigrant-focused policies as drivers of Latino health disparities in the United States. *Social Science & Medicine* 199: 29–38.

Ponic P, Varcoe C and Smutylo T (2016) Trauma-(and violence-) informed approaches to supporting victims of violence: policy and practice considerations. Available at: http://www.justice.gc.ca/eng/rp-pr/cj-jp/victim/rd9-rr9/p2.html

Power N and Franck L (2008) Parent participation in the care of hospitalized children: a systematic review. *Journal of Advanced Nursing* 62: 622–641.

Rasanathan K and Diaz T (2016) Research on health equity in the SDG era: the urgent need for greater focus on implementation. *International Journal for Equity in Health* 15: 1–3.

Rasmussen S, Water T and Dickinson A (2017) Children's perspectives in family-centred hospital care. *Contemporary Nurse* 53: 445–455.

Representative for Children and Youth (2014) *Not fully invested: A follow-up report on the representative's past recommendations to help vulnerable children in B.C.* [Online]. Victoria, BC: Author. Available at: https://www.rcybc.ca/sites/default/files/documents/pdf/reports_publications/rcy-recreport2014-revisedfinal.pdf (accessed 23 November 2014).

Representative for Children and Youth and office of the Provincial Health Officer (2015) Growing up in B.C. Retrieved from: https://www.rcybc.ca/sites/default/files/documents/pdf/reports_publications/guibc-2015-finalforweb_0.pdf?utm_source=E-News+Contacts&utm_campaign=ac1527cea9-BCACCS+E-News+for+June+23%2C+2015&utm_medium=email&utm_term=0_0bdd35ef3a-ac1527cea9-88221037

Schleiff M, Kumapley R, Freeman PA, et al. (2017) Comprehensive review of the evidence regarding the effectiveness of community–based primary health care in improving maternal, neonatal and child health: 5. equity effects for neonates and children. *Journal of Global Health* 7: 388–401.

Shields L, Zappia T, Blackwood D, et al. (2012) Lesbian, gay, bisexual, and transgender parents seeking health care for their children: a systematic review of the literature. *Worldviews on Evidence-Based Nursing* 9: 200–209.

Shonkoff JP (2012) Leveraging the biology of adversity to address the roots of disparities in health and development. *Proceedings of the National Academy of Sciences* 109: 17302–17307.

Sick Kids (2014) Model of child and family-centred care. Available at: http://www.sickkids.ca/patient-family-resources/child-family-centred-care/59043-54345%20stat%20CFCCmodel4.pdf

Smith JP, Shields L, Neill SJ, et al. (2017) Losing the child's voice and 'the captive mother': an inevitable legacy of family-centred care? *Evidence-Based Nursing* 0: 1–3.

Smye V, Browne AJ, Varcoe C, et al. (2011) Harm reduction, methadone maintenance treatment and the root causes of health and social inequities: an intersectional lens in the Canadian context. *Harm Reduction Journal* 8: 17.

Smylie J Fell D and Ohlsson A (2010) A review of aboriginal infant mortality rates in Canada: striking and persistent aboriginal/non-aboriginal inequities. *Canadian Journal of Public Health*. Available at: https://journal.cpha.ca/index.php/cjph/article/viewFile/2370/2127 [Online].

Stewart M., King M, Blood R, et al. (2013) Health inequities experienced by aboriginal children with respiratory conditions and their parents. *Canadian Journal of Nursing Research* 45: 6–27.

Varcoe C and Browne AJ (2015) Culture and cultural safety: beyond cultural inventories. In: Gregory D, Raymond-Seniuk L, Patrick L, et al. (eds). *Fundamentals: Perspectives on the Art and Science of Canadian Nursing*. Philadelphia: Lippincott.

Varcoe C and Doane G (2015) The significance of context: relational inquiry and family nursing in Canada. In: Kaakinen JR, Gedaly-Duff V, Coehlo DP, et al. (eds). *Family Health Care Nursing: Theory, practice, and Research*. Philadelphia, PA: F A Davis.

Varcoe C, Wathen CN, Ford-Gilboe M, et al. (2016) *VEGA Briefing Note on Trauma-and Violence-Informed Care*. Available at: http://projectvega.ca/wp-content/uploads/2016/10/VEGA-TVIC-Briefing-Note-2016.pdf

Wilson D, Heaslip V and Jackson D (2017) Improving equity and cultural responsiveness with marginalised communities: understanding competing worldviews. *Journal of Clinical Nursing* 27: 3810–3819.

Wong S, Browne AJ, Varcoe C, et al. (2014) Development of health equity indicators in primary health care organizations using a modified delphi. *Plos One* 9: 1–15.

Wood DL and Goldhagen JL (2013) Promoting child health equity: family-centered care coordination is just one piece of the puzzle. *Pediatrics*. Available at: 10.1542/peds.2012-3248 [Online].

World Health Organization (2008) *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health*. Geneva, Switzerland: Commission on Social Determinants of Health Final Report. Available at: http://apps.who.int/iris/bitstream/10665/43943/1/9789241563703_eng.pdf (accessed 18 December 2010).

World Health Organization (2013) Closing the health equity gap: policy options and opportunities for action. Available at: https://www.cdc.gov/nchhstp/socialdeterminants/docs/who-closing-health-equity-gap-policy-opportunities-.pdf

Wright A, Jack S, Ballantyne M, et al. (2019) Indigenous mothers' experiences of using primary care in Hamilton, Ontario, for their infants. *International Journal of Qualitative Studies on Health and Well-being* 14: 1–14.